

Dialysis Center CAHPS- In-center Hemodialysis Patient Survey

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Melding Measurement and Improvement



■ CMS's Quality Strategy:

- Define quality through standardized performance measures
- Plans and providers measure care
- Create data standards and infrastructure for measurement, quality improvement, and public reporting

Goals of CAHPS® Surveys



- **Create a public domain tool for public reporting and accountability so comparable information will be available across provider types**

Need for a Standardized Survey for Dialysis Patients



- CMS is interested in producing valid comparative information on providers for consumer choice and adding the patient's perspective to the clinical information already available to dialysis patients
- This requires a core set of standard questions administered in a uniform manner to eligible patients selected according to the same criteria

CMS and AHRQ's CAHPS Collaboration



- AHRQ and CMS have collaborated for almost 10 years on the CAHPS project—focus on obtaining the consumer/patient perspective on quality
- 3 grantees, nationally renowned for their survey research expertise (AIR, RAND, and Harvard) were selected for CAHPS II through an open, competitive process
- Since its inception in 1995, CAHPS has established a rigorous evidence-based process to create surveys, methods of administration, and reports of results to consumers and providers

CMS and AHRQ's CAHPS Collaboration



- **Health plan CAHPS is used by the commercial, Medicaid and Medicare programs covering over 123 million Americans and is the national standard**
- **CMS is also working with AHRQ to produce surveys for Nursing Home residents and their families, Hospital patients, enrollees of Preferred Provider Organizations and members of Medicare Prescription Drug Plans.**

Key Features of CAHPS® Approach



- **Collaborative approach**
 - Within CAHPS team
 - With other organizations
- **Emphasis on testing and evaluation**
- **Reliance on user input**
- **Free and open access to standardized instruments**
- **CAHPS® owned by AHRQ**
- **Technical assistance to users**

Standard CAHPS® Development Process



- **Rigorous process of scientific research that includes:**
 - a call for measures
 - review of existing literature
 - cognitive interviews
 - testing of the draft instrument
 - psychometric analysis
 - consumer focus groups
 - public input in response to Federal Register notices
 - stakeholder input

End-stage Renal Disease



- End-stage renal disease (ESRD) is the only disease-specific entitlement under the Medicare Program.
- U.S. Renal Data System (USRDS) reported that over 406,000 Americans were diagnosed with ESRD at the end of 2001 (USRDS, 2003).
- About 375,000 receiving dialysis in 4000 facilities.
- Medicare's share of the cost of ESRD was \$15.4 billion in 2001, with another \$7.4 billion borne by patients and health plans (USRDS, 2003).

End-stage Renal Disease



- **ESRD program consumes ever-increasing proportion of the Medicare budget – 6.4% in 2001 (USRDS, 2003).**
- **Numbers of patients with kidney disease expected to continue increasing since associated with aging, diabetes and high blood pressure.**
- **ESRD population is growing about 6% per year.**
- **By 2010 it is estimated that approx. 520,000 Americans will be receiving dialysis treatment for ESRD.**

What is ESRD?



- Most or all of kidney function has been lost, death will occur within a few weeks if not treated.
- End-stage renal disease = end of kidney life, not the end of a patient's life.
- Moving toward use of term Chronic Kidney Disease (CKD) – ESRD or Kidney Failure is stage 5 of CKD.

Treatment of ESRD - 1



- **Three treatment choices for patients with ESRD:**
 - Hemodialysis,
 - Peritoneal Dialysis and
 - Transplant

Treatment of ESRD - 2



- **Hemodialysis – a machine does the work of the kidneys to clean and filter the blood**
 - Usually done at a dialysis center, but can be done at home.
 - At least three times per week for about 4 hours each visit.
 - These patients spend a lot of time in dialysis facilities, interacting with staff!

Treatment of ESRD - 3



- **Peritoneal Dialysis – uses the lining of the abdomen to filter the blood.**
 - Patients can administer to themselves at home or work.
 - Done several times per day.
 - Facilities support patients with education and supplies.

Treatment of ESRD - 4



■ Kidney Transplant

- Preferred treatment for Kidney Failure
- From a living or cadaveric donor
- Lack of donors means more patients need dialysis

People with ESRD -1



- Complex Condition
- Comorbid conditions such as diabetes, high BP, heart disease, heart failure, depression, cognitive impairment, vision problems
- Hospitalization – average 17 days per year
- Takes average of 8 different medications – some as many as 16
- Five year survival rate below 50%

People with ESRD - 2

■ Race

- Black 37%
- White 54%
- Others also affected Hispanic, Native American, Asian/Pacific Islander

■ Gender

- Male 54%
- Female 46%

People with ESRD - 3

■ Education levels

- 39% less than high school
- 30% finished high school
- 30% some college or higher

■ Age:

- under 60 45%
- 60 – 79 45%
- ≥ 80 10%

Dialysis Centers and ESRD Networks



■ Dialysis Centers:

- There are 3555 free-standing (80%), and 878 hospital-based facilities (20%)
- 47% have under 50 or fewer patients, 37% having 51-100 patients, and 17% with over 100 patients per facility.

■ ESRD Networks (like QIOs):

- under contract with CMS, assist the dialysis centers with quality improvement activities.
- There are 18 Networks across the country

Mandate for CAHPS - 1



- **BBA 1997 – Secretary of HHS should measure and report the quality of dialysis services**
 - Dialysis Facility Compare – posts facility-specific quality information and facility characteristics on www.medicare.gov/dialysis/home.asp

Mandate for CAHPS - 2



- **The Office of the Inspector General (OIG) Report entitled “External Review of Dialysis Facilities” (June 2000),**
- **MedPAC Report to Congress entitled “Improving Payment for End Stage Renal Disease Services” (March 2000),**
- **MedPAC Report to Congress "Modernizing the Outpatient Dialysis Payment System" (October 2003)**
- **“Crossing the Quality Chasm”, the Institute of Medicine (IOM) 2001**

Mandate for CAHPS - 3



- **Senator Grassley corresponds regularly with HHS Sec. Tommy Thompson regarding dialysis patients**
- **DFC Evaluation – what do patients want to know about dialysis centers? What other patients think about the center is the #1 request**
- **Pt Experience of Care measures notably absent from current ESRD measure set**

CAHPS Approach to Survey Development



- Ask patients only those questions for which they are the best or only source of information. Emphasize reporting of their actual experiences.
- Provide information that is useful and relevant to consumers
- Evidence-based, use of the best science in survey and reports, including cognitive and field testing
- Input from all affected parties
- Standardization--create a core set of items that apply to all of the providers in questions (e.g., all facilities, all health plans) and the option of adding supplemental questions to address more specific needs
- Public resource—all CAHPS tools, resources, and services are in the public domain

Development of ICH CAHPS



- Many facilities currently conduct their own surveys for quality improvement
- CMS supports such quality improvement efforts
- In light of this, CMS approached AHRQ to first determine if a survey could address both patient public reporting and facility internal quality improvement needs
- Focus on in-center hemodialysis patients
- Because these patients have a great deal of experience getting care, could report on a range of events relevant to both QI and patient reports

Feasibility Report



- Literature review
- Focus groups with patients and their families
- Focus groups with nephrologists
- Interviews with Network executive directors and facility administrators
- Discussion with TEP to get input on content and purpose of patient survey
- Review of draft report by TEP
- Submission to CMS, October 2003; CMS acceptance, December 2003

Major Findings of Feasibility Report: Purpose and Use of Survey



- Strong to moderate support among all constituencies for a standardized survey
- Most stakeholders thought survey would be of little use to patients for facility choice, but patients disagreed
- Concerns about a new survey include: effects of replacement of existing surveys, accuracy of patient feedback, and cost

Major Findings of Feasibility Report: Domains and Item Content



- Communication with patients
- Education of patients
- Patient involvement in care
- Coordination of care
- Patient perception of staff proficiency
- Patient safety
- Facility amenities and environment
- Access and convenience of care including transportation
- Handling of complaints

Major Findings of Feasibility Report: Methods and Survey Administration



- **Site of survey administration (at home, at facility)**
- **Low literacy levels, fatigue, cognitive impairment, and poor vision obstacles to self administration**
- **Frequent interaction of dialysis patients with one another and staff creates unique culture to consider when administering a survey**

Major Recommendations of Feasibility Report to CMS



- Take steps to ensure that ESRD community is appropriately involved in survey development and their concerns addressed
- Focus on in-center hemodialysis initially, and address both public reporting and quality improvement
- Survey in English and Spanish; assess need for other languages
- Careful consideration of which items are and are not under facility control
- Support of efforts to determine how patients and providers will use the report
- Independent 3rd party administration of survey
- Determination of patient eligibility for inclusion in survey
- Include mode test in pilot test
- ²⁹ Investigation of use of assistance to complete survey

Survey Development Process



- **Federal Register call for measures, August-October 2003, 12 instruments received; 16 reviewed in all**
- **CAHPS team reviews instruments for reliability, validity, breadth and magnitude of use, scientific soundness, testing completed, etc.**
- **All items from submitted surveys entered into one comprehensive database by topic areas (e.g., patient education) that were identified through the literature review, existing surveys and TEP**
- **Instrument team meets weekly beginning in November through the present; in-person meeting in December, CMS renal clinicians involved**

Survey Development Process (continued)



- Six full iterations of survey before cognitive testing draft produced
- Cognitive testing conducted in 3 locations across country, February 2004
- Instrument revised again after cognitive testing
- Public comment through Federal Register notice released January 30-March 30 2004
- CMS and TEP reviewed revised version mid-March
- Comments provided at ESRD Stakeholders meeting in March 2004

Survey Development Process (continued)



- Revised instrument and conducted additional cognitive testing, June 2004
- Translated into Spanish and conducted cognitive testing in Spanish, August 2004
- TEP review of version 15, September 2004
- Pilot test January-March 2005
- Additional revisions as a result of pilot test findings

Survey Development Process: Pilot Test



- **January-March 2005**
- **Sample of 30 facilities chosen from a list of all 4400 facilities, stratified by size, region of country (NE, South, Midwest, West), rural/urban location, part of LDO or not, racial/ethnic mix of patients including Spanish speakers, hospital based/free-standing, profit/non-profit**
- **Patients with 3 months or more of experience at current facility; N=3000**
- **Sample--For facilities with up to 150 patients, will take the census; over 150, simple random sample of patients**

Survey Development Process: Pilot Test (continued)



- **Mode test—telephone only and mixed mode (mail with telephone follow up)**
- **Proxies—Systematic testing and comparison of results for those using assistance of family/friends/staff**
- **Psychometric testing**
- **Non-response analysis by gender, age, race/ethnicity, length of time at current facility, total length of time on hemodialysis**

Revisions of Survey After Pilot



- **Examine inter-item correlations; conduct factor analysis**
- **Determine which items discriminate**
- **Shorten further**
- **Submit to CMS for consideration for national implementation**

Exploratory QI Project



- **2 facilities in each of 3 Networks selected by CMS will participate. A set of matched facilities from the pilot test that are not engaging in a CAHPS QI project will serve as comparisons**
- **Networks and facilities will work together to design and implement a QI project using their ICH CAHPS results from the pilot test**
- **Each Network will have a CAHPS grantee to advise them**
- **A lessons learned document will be produced at the end of the project to summarize key challenges and successful strategies**

Immediate Next Steps



- **Implement pilot**
- **Begin creation of consumer and provider reports; conduct focus groups**
- **Use results from pilot test to launch planned exploratory QI intervention with selected Networks and facilities**
- **Submission of completed survey to CMS in late Spring**
- **CMS will consider alternatives for implementation**

QUESTIONS?



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Thank you!